

Myelomeningocele (Spina Bifida)

Condition: Myelomeningocele (MM) is a type birth defect where the spine does not close all the way before birth, causing parts inside the spinal column to bulge out of the body. It is the most severe type of spina bifida.

Background: Only about two of every 10,000 newborns have MM. Tests done during pregnancy can diagnose it before birth.

Risk Factors: Not having enough of a vitamin called folic acid can lead to MM. Obesity, diabetes, hyperthermia, and some medications also increase the risk. If one baby in a family has been born with MM, later babies are at higher risk.

History and Symptoms: In babies with MM, a sac may stick out of the back where the spine did not close. There can also be extra fluid in the brain, making the baby's head large. These defects can cause problems with feeding, breathing, behavior and growth. They can also suffer headaches, vomiting, numbness, bladder and bowel incontinence, weakness, and even paralysis.

Physical Exam: The doctor will check the baby's eyes, muscle strength, reflexes, and sensation. As the child grows, the doctor will keep track of head size, growth, bladder and bowel function, movement, thinking, behavior, mood, and social function.

Diagnostic Process: Blood tests are used to see if the kidneys are working well. X-rays, ultrasound, CT and MRI of the spine and brain may be done to get a better idea of how severe the defect is. Other tests may be needed to see how the urinary tract is working.

Rehab Management: Surgery is often done in the first few days after birth. If a child has fluid in the brain, a tube may be placed from the skull to the abdomen to drain the fluid away. Many types of therapy may be needed to help the child grow and lead full, productive lives.

Since MM can affect many body functions throughout the person's lifetime, having a physical medicine and rehabilitation (PM&R) physician is highly recommended. PM&R physicians can treat patients of all ages, create a treatment plan that helps with function, and facilitate care coordination with other medical professionals. They may prescribe appropriate equipment, including braces, walkers and wheelchairs. They can manage skin, bowel and bladder complications.

Other Resources for Patients and Families: Families may get help from social workers, the Spina Bifida Association and the Spina Bifida Resource Network.

Frequently Asked Questions

What is PM&R?

Physical medicine and rehabilitation (PM&R), also known as physiatry, is a primary medical specialty that aims to enhance and restore functional ability and improve quality of life to those with injuries, physical impairments or disabilities affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles and tendons. PM&R physicians, known as physiatrists, evaluate and treat the whole body, maximize patients' independence in their daily life and are experts in designing comprehensive, patient-centered treatment plans to empower patients to achieve their goals. By taking the whole body into account, they can accurately pin-point problems, decrease pain, assist in recovery from devastating injuries and maximize overall outcomes and performance with non-surgical and peri-surgical options. To learn more, visit www.aapmr.org/aboutpmr.

What makes PM&R physicians unique?

PM&R physicians' training focuses not just on treating medical conditions, but on enhancing the patient's performance and quality of life in the context of those medical conditions. They focus not only on one part of the body, but instead on the development of a comprehensive program for putting the pieces of a person's life back together – medically, socially, emotionally and vocationally – after injury or disease. PM&R physicians make and manage medical diagnoses, design a treatment plan and prescribe the therapies that physical therapists or other allied therapists perform or that are carried out by the patients themselves. By providing an appropriate treatment plan, PM&R physicians help patients stay as active as possible at any age. Their broad medical expertise allows them to treat disabling conditions throughout a person's lifetime.

Why see a PM&R physician?

A PM&R physician will thoroughly assess your condition, needs, and expectations and rule out any serious medical illnesses to develop a treatment plan. By understanding your condition and goals, you and your PM&R physician can develop a treatment plan suited to your unique needs.

How do I find a PM&R physician near me?

Visit www.aapmr.org/findapmrphysician or contact your primary care physician for a referral.